

Data to Care Protocol

Context

Data to Care is a joint initiative with HIV Surveillance, Prevention, Care Services and STD Prevention and Surveillance. Persons living with HIV (PLWH) who are not in care are at a greater risk for poor health outcomes, premature death and transmitting HIV. The purpose of “Data to Care” (DtC) is to use HIV surveillance data to identify PLWH who are not in care, link them to care, and support the HIV Care Continuum. Historically, HIV surveillance data have been used to monitor and characterize the HIV epidemic both locally and nationally. DtC reflects a shift from the typical use of HIV surveillance data to using the data to improve health outcomes for PLWH. The ultimate goals of DtC are to increase the number of PLWH who are: 1) engaged in HIV care and 2) have an undetectable viral load.

The DtC Initiative utilizes the Care Markers Database (CMDB) to create lists of people who appear to be out of care (OOC) within a specified time frame. Once a list has been produced, the Division of Disease Prevention (DDP) will transmit information securely to Disease Intervention Specialists (DIS) or designated personnel at local health departments (LHDs), medical sites or community-based organizations (CBOs) that provide re-engagement and linkage services. The OOC lists that are generated for all sites will **only** include clients who have had a documented relationship with that facility, with the exception of the DIS. This document specifies a protocol for personnel to contact OOC individuals.

Prior to beginning follow-up of OOC persons, all staff will be trained on the DtC protocol and the process of entering data collected during follow up. This training will detail the expectation of tasks, and contact persons within DDP, and data entry into the DtC module in the DDP REDCap system.

Eligibility

Clients are eligible for the OOC list if they are:

1. HIV-positive and reported to the HIV Surveillance database (eHARS);
2. 18 years of age or older;
3. Living with a last known address in Virginia; and
4. Meet the OOC Definition:
 - a. Have evidence of care via a reported care marker in the reference year but no evidence of care within one year (365 days) from the date that the OOC list was generated. For example: Clients would only be considered OOC in January 2021 if they had evidence of care in 2019 (the reference year) but no evidence of care in 2020. If the OOC list was generated on 01/01/2021, clients who do not have a care marker reported from 01/01/2020-12/31/2020 would appear on the OOC list. Care markers are considered to be any of the following occurring on or after the day of HIV diagnosis:

- a. CD4 count
- b. Viral Load
- c. HIV medical care visit
- d. Antiretroviral therapy (ART) prescription
- e. HIV genotype sequencing

Process

- **Step 1: Generating OOC List**

Lists of OOC persons will be generated from the CMDB by DDP HIV Surveillance staff. Persons who are deceased and who are no longer living in Virginia, as reported to eHARS, will be removed. The data from eHARS will be merged with the CMDB to determine persons who had a care marker in the reference year, but no evidence of care within the one-year timeframe (See example in #4 above).

The list will be then matched with the AIDS Drug Assistance Program database (ADAP) database, STD*MIS/MAVEN interview records, DC-Maryland-Virginia Data Exchange records, and batch-match data from Accurint® (LexisNexis®) to check for updated address, vital status, and other contact information. Persons who are found to have an out-of-state address or a populated death date after this round of matching are removed from the list. The remaining clients are considered eligible for the OOC list.

All eligible clients (including clients investigated by DIS) will be assigned a unique ID called a “Data to Care number” that will be entered on the DtC form. This unique ID does not contain any personal health information (PHI) and will be used to track forms as they are entered into the REDCap System and ultimately stored in the Care Markers Database.

Lists will be generated for each participating CBO, LHD, and medical site trained in the DtC protocol with OOC clients who have been identified as receiving care at their specific provider site. The OOC clients who do not have an identified medical or services provider will have field records initiated for DIS investigation.

The OOC lists will include the following:

- Data to Care number
- eHARS STATENO (**DIS only**)
- Last known Medical Provider (from REDCap, the AIDS Drug Assistance Program (ADAP), PreventionWeb, Medicaid or eHARS)
- First Name
- Middle Name
- Last Name
- Date of Birth
- Gender (sex at birth from eHARS)
- Race/Ethnicity
- Social Security Number (if available)
- Date of HIV Diagnosis
- Health District of Current Residence
- Health Department of Current Residence

- Last Date of Service (from REDCap or ADAP)
 - Most recent Care Marker Date
 - eHARS Current Street Address and Phone Number
 - REDCap Address, Address Date, Phone Number and Email Address (if applicable)
 - ADAP Address
 - STD*MIS/MAVEN Address, Phone Number, Address Date
 - LexisNexis Address, Phone Number, Address Date
- **Step 2: OOC List Distribution**
 - **Agency staff:** DDP DtC staff will securely send OOC lists to all agencies, LHDs and medical facilities. Agency Administrators only will receive the OOC list and disseminate to linkage staff as appropriate. Agency administrators must save the OOC list in a secure folder within their agency's network and comply with VDH's Security and Confidentiality Guidelines for handling sensitive client information.
 - **DIS only:** DDP DtC staff will provide the OOC list to the Regional STD Program Coordinator (RSPC), who will initiate Field Records (FRs) with Interview Only indicated, and provide to Field Operations staff. It is required that both the FR number and the Data to Care number be entered into the DDP REDCap System for each client investigated by the DIS. The DIS will be responsible for investigating OOC clients whose last known residence is within the DIS' catchment area and do not have medical provider information available or whose last known medical provider is not a contractor of VDH. DDP DtC staff will discuss current DIS caseload prior to distribution of OOC lists to ensure current DIS caseload and DtC investigation can be met.
 - DDP will provide all agencies with the most up-to-date client contact information for all clients on the OOC lists. Each client will be assigned a unique ID called a Data to Care number that will be entered into the client's record in REDCap. This unique ID does not contain any personal health information (PHI) and will be used to track client DtC records as they are entered into REDCap ultimately imported in the CMDB.
 - DDP will maintain a copy of OOC lists sent to DIS, CBOs, LHDs, and medical sites with the date the OOC list was disseminated to each site.
 - Lists sent to agencies will not contain more than 50 clients. Any list greater than 50 clients will be split, with excess clients sent to DIS or moved to the subsequent OOC list.
 - **Step 3: Client Follow-up**
 - **Time Frames:** The maximum duration for agencies to investigate each client on an OOC list is 60 days. All investigations and outcomes should be documented electronically in the DDP REDCap System (previously e2Virginia). If OOC list investigation exceeds 60 days, DDP DtC staff, DDP contract monitors and agency supervisors will reassess the OOC list follow-up and will develop a plan for continued DtC follow-up, including feasible timeframes, on an as-needed basis.

- **Contact Attempts:**
 - a. **Number of Contact Attempts:** Staff will attempt to contact the client a minimum of three times. Staff must exhaust all possible avenues until they either locate and speak with the client or determine that a client is deceased, has moved out of state, or is unable to be located.
 - b. **Contact Methods:** Staff should only use methodologies consistent with their agency's standard practices. Contact methods could include: review of internal medical records, phone calls, text messages, emails, letters, field visits, and social media.
 - Phone calls and texting may be continued if there are indicators that the phone number is in use by the OOC client (e.g. if the voicemail message indicates the name of the client) as long as the investigation remains open.
 - Field visits should not be initiated before other contact attempts in order to inform the client that the agency or health department is attempting to contact the patient about a health related issue, and to expect a field visit if they do not respond.
 - Multiple field visits may have to be made at different times of the day if there is evidence that the client is living at the location.
 - Investigators should attempt to make at least one face-to-face encounter with the client.
 - **Staff should follow their agency's safety policies and procedures when conducting field visits.**
- **Referral to Care/Services (For DIS Only, Using Active Referral Protocol):** This stage in the protocol will be enacted as the DIS locates persons who are not in care and agree to receive linkage services. Using the DDP REDCap System, the DIS will assess the client's barriers to care, as well as their need for other services. The DIS will then follow the steps of the Active Referral Protocol to link the client to the needed services. Once the client has attended their first medical visit, the DIS will ensure all information is entered into the DDP REDCap System.
- **Step 4: Data Collection in REDCap**

Staff will use the DtC form within the DDP REDCap System to document their progress in attempting to contact the client. As a result of these attempts, staff will assign the client one of eight outcomes on the Data to Care form (by the end of the 60 day time frame, if not sooner). Final Client Outcomes include:

 1. *Client located and currently in medical care within last 12 months* (If the client has a scheduled upcoming appointment then provide the appointment date, name of medical facility, and name of medical provider, and phone number and address of

- the facility. **Note: if it cannot be verified that the patient is currently in care, then do not select this outcome)**
2. *Client was located and not in care* (Check boxes associated with barriers to care; and identify whether client is currently in the process of reengaging, wants to reengage, or refuses care)
 3. *Client moved out of state* (provide the state of current residence, current address, and month and year of move, if available)
 4. *Client is deceased* (provide date of death and source of death information)
 5. *Client is incarcerated* (provide facility name and expected date of release; If the client's expected date of release is within 6 months of the date the investigator has found the information, then the investigator must refer the client to CHARLI or Care Coordination.)
 6. *Client was unable to be located*
 7. *Client was discharged* (provide date of discharge and what facility the client was discharged to; Do not contact the facility where the client was discharged to confirm)
 8. *Other:* (please specify; select this outcome for any situation that does not fit any of the above outcomes)
- **Step 5: Closing the Investigation**
 - If the client cannot be located, is located and in care, or is located and refuses services, staff can then close the case. Staff should complete data entry in the DDP REDCap System, documenting tracking, contact attempts and appropriate outcome.
 - If the client is located in Virginia, but outside the usual catchment area of the agency, staff will follow up according to methodologies consistent with that agency's standard practice. (**DIS Only:** DIS will work with the field supervisor to determine on a case-by-case basis if the investigation will continue.)
 - **Coordination of Care and Services Agreement (CCSA):** If the client is located and not in care, staff may ask the client to sign the CCSA, explaining that if the client experiences difficulty maintaining engagement with care in the future, signing the document will ease the process of providing assistance to get back in medical care. The CCSA is not required; however, clients must provide consent to provide referrals. Agencies may choose to use their own consent form instead of the CCSA. Staff should document whether the client signed the CCSA in the DDP REDCap system. Updated client contact information should also be entered in the DDP REDCap System.

Contact Information

Please direct all DtC questions to the contact information below:

Virginia Department of Health
Attn: Miesha Houston, Data to Care Linkage Coordinator
109 Governor St
Richmond, VA 23219
Phone Number: (804) 864-7862

Email: miesha.houston@vdh.virginia.gov

Security and Confidentiality

The Virginia Department of Health (VDH) and Division of Disease Prevention (DDP) adhere to all security and confidentiality guidelines as outlined by the DDP Data S&C Policies and Procedures (https://www.vdh.virginia.gov/content/uploads/sites/10/2016/01/DDP_Security_and_Confidentiality_Policies_and_Procedures.pdf) and are compliant with the Health Insurance Portability and Accountability Act (HIPAA). Contracted agencies should strictly adhere to all confidentiality guidelines when working with protected patient information.

Internal

- **Data Processing:**

Data extracts of DtC data will be available to staff on an as-needed basis. Further, monthly data extracts of DtC data will be imported into the CMDB. Access to data will only be granted to staff with a legitimate business need.

- **Generation of new lists:**

OOC lists for sites participating in DtC activities will be generated quarterly, using the OOC data and data from the DtC form in the CMDB. Those who have been confirmed as in care, deceased, and moved out of state will be removed from future lists for the site. Those who have been identified with upcoming appointments, re-linked to care, or as not located will continue to appear on the lists, but with the information from the previous DtC follow-up record.